

109TH CONGRESS  
1ST SESSION

# H. R. 3248

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JULY 12, 2005

Mr. FERGUSON (for himself, Mr. LANGEVIN, Mr. TERRY, Mr. NORWOOD, Mrs. WILSON of New Mexico, and Mr. BROWN of Ohio) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as the “Lifespan Respite Care  
5       Act of 2005”.

6       **SEC. 2. LIFESPAN RESPITE CARE.**

7       The Public Health Service Act (42 U.S.C. 201 et  
8       seq.) is amended by adding at the end the following:

**“TITLE XXIX—LIFESPAN  
RESPITE CARE**

**“SEC. 2901. DEFINITIONS.**

“In this title:

“(1) ADULT WITH A SPECIAL NEED.—The term  
‘adult with a special need’ means a person 18 years  
of age or older who requires care or supervision to—

“(A) meet the person’s basic needs; or

“(B) prevent physical self-injury or injury  
to others.

“(2) CHILD WITH A SPECIAL NEED.—The term  
‘child with a special need’ means a person less than  
18 years of age who requires care or supervision be-  
yond that required of children generally to—

“(A) meet the child’s basic needs; or

“(B) prevent physical self-injury or injury  
to others.

“(3) ELIGIBLE RECIPIENT.—The term ‘eligible  
recipient’ means—

“(A) a State agency;

“(B) any other public entity that is capa-  
ble of operating on a statewide basis;

“(C) a private, nonprofit organization that  
is capable of operating on a statewide basis;

1 “(D) a political subdivision of a State that  
2 has a population of not less than 3,000,000 in-  
3 dividuals; or

4 “(E) any recognized State respite coordi-  
5 nating agency that has—

6 “(i) a demonstrated ability to work  
7 with other State and community-based  
8 agencies;

9 “(ii) an understanding of respite care  
10 and family caregiver issues; and

11 “(iii) the capacity to ensure meaning-  
12 ful involvement of family members, family  
13 caregivers, and care recipients.

14 “(4) FAMILY CAREGIVER.—The term ‘family  
15 caregiver’ means an unpaid family member, a foster  
16 parent, or another unpaid adult, who provides in-  
17 home monitoring, management, supervision, or  
18 treatment of a child or adult with a special need.

19 “(5) LIFESPAN RESPITE CARE.—The term ‘life-  
20 span respite care’ means a coordinated system of ac-  
21 cessible, community-based respite care services for  
22 family caregivers of children or adults with special  
23 needs.

24 “(6) RESPITE CARE.—The term ‘respite care’  
25 means planned or emergency care provided to a

1 child or adult with a special need in order to provide  
2 temporary relief to the family caregiver of that child  
3 or adult.

4 **“SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOP-**  
5 **ERATIVE AGREEMENTS.**

6 “(a) PURPOSES.—The purposes of this section are—

7 “(1) to expand and enhance respite care serv-  
8 ices to family caregivers;

9 “(2) to improve the statewide dissemination and  
10 coordination of respite care; and

11 “(3) to provide, supplement, or improve access  
12 and quality of respite care services to family care-  
13 givers, thereby reducing family caregiver strain.

14 “(b) AUTHORIZATION.—Subject to subsection (e), the  
15 Secretary is authorized to award grants or cooperative  
16 agreements to eligible recipients who submit an applica-  
17 tion pursuant to subsection (d).

18 “(c) FEDERAL LIFESPAN APPROACH.—In carrying  
19 out this section, the Secretary shall work in cooperation  
20 with the National Family Caregiver Support Program Of-  
21 ficer of the Administration on Aging and other respite care  
22 program officers within the Department to ensure coordi-  
23 nation of respite care services for family caregivers of chil-  
24 dren and adults with special needs.

25 “(d) APPLICATION.—

1           “(1) SUBMISSION.—Each eligible recipient de-  
2           siring to receive a grant or cooperative agreement  
3           under this section shall submit an application to the  
4           Secretary at such time, in such manner, and con-  
5           taining such information as the Secretary shall re-  
6           quire.

7           “(2) CONTENTS.—Each application submitted  
8           under this section shall include—

9                   “(A) a description of the applicant’s—

10                           “(i) understanding of respite care and  
11                           family caregiver issues;

12                           “(ii) capacity to ensure meaningful in-  
13                           volvement of family members, family care-  
14                           givers, and care recipients; and

15                           “(iii) collaboration with other State  
16                           and community-based public, nonprofit, or  
17                           private agencies;

18                   “(B) with respect to the population of fam-  
19                   ily caregivers to whom respite care information  
20                   or services will be provided or for whom respite  
21                   care workers and volunteers will be recruited  
22                   and trained, a description of—

23                           “(i) the population of family care-  
24                           givers;

1 “(ii) the extent and nature of the res-  
2 pite care needs of that population;

3 “(iii) existing respite care services for  
4 that population, including numbers of fam-  
5 ily caregivers being served and extent of  
6 unmet need;

7 “(iv) existing methods or systems to  
8 coordinate respite care information and  
9 services to the population at the State and  
10 local level and extent of unmet need;

11 “(v) how respite care information dis-  
12 semination and coordination, respite care  
13 services, respite care worker and volunteer  
14 recruitment and training programs, or  
15 training programs for family caregivers  
16 that assist such family caregivers in mak-  
17 ing informed decisions about respite care  
18 services will be provided using grant or co-  
19 operative agreement funds;

20 “(vi) a plan for collaboration and co-  
21 ordination of the proposed respite care ac-  
22 tivities with other related services or pro-  
23 grams offered by public or private, non-  
24 profit entities, including area agencies on  
25 aging;

1 “(vii) how the population, including  
2 family caregivers, care recipients, and rel-  
3 evant public or private agencies, will par-  
4 ticipate in the planning and implementa-  
5 tion of the proposed respite care activities;

6 “(viii) how the proposed respite care  
7 activities will make use, to the maximum  
8 extent feasible, of other Federal, State,  
9 and local funds, programs, contributions,  
10 other forms of reimbursements, personnel,  
11 and facilities;

12 “(ix) respite care services available to  
13 family caregivers in the applicant’s State  
14 or locality, including unmet needs and how  
15 the applicant’s plan for use of funds will  
16 improve the coordination and distribution  
17 of respite care services for family care-  
18 givers of children and adults with special  
19 needs;

20 “(x) the criteria used to identify fam-  
21 ily caregivers eligible for respite care serv-  
22 ices;

23 “(xi) how the quality and safety of  
24 any respite care services provided will be  
25 monitored, including methods to ensure

1           that respite care workers and volunteers  
2           are appropriately screened and possess the  
3           necessary skills to care for the needs of the  
4           care recipient in the absence of the family  
5           caregiver; and

6           “(xii) the results expected from pro-  
7           posed respite care activities and the proce-  
8           dures to be used for evaluating those re-  
9           sults; and

10          “(C) assurances that, where appropriate,  
11          the applicant shall have a system for maintain-  
12          ing the confidentiality of care recipient and  
13          family caregiver records.

14          “(e) PRIORITY.—When awarding grants or coopera-  
15          tive agreements under this section, the Secretary shall give  
16          priority to—

17               “(1) applicants that show the greatest likeli-  
18               hood of implementing or enhancing lifespan respite  
19               care statewide; and

20               “(2) applicants from States that are not other-  
21               wise receiving a grant under this title.

22          “(f) USE OF GRANT OR COOPERATIVE AGREEMENT  
23          FUNDS.—

24               “(1) IN GENERAL.—



1           “(A) MANDATORY USES OF FUNDS.—Each  
2 eligible recipient that is awarded a grant or co-  
3 operative agreement under this section shall use  
4 the funds, unless such a program is in exist-  
5 ence—

6                   “(i) to develop lifespan respite care at  
7 the State and local levels;

8                   “(ii) to provide respite care services  
9 for family caregivers caring for children or  
10 adults;

11                   “(iii) to train and recruit respite care  
12 workers and volunteers;

13                   “(iv) to provide information to care-  
14 givers about available respite and support  
15 services; and

16                   “(v) to assist caregivers in gaining ac-  
17 cess to such services.

18           “(B) DISCRETIONARY USES OF FUNDS.—  
19 Each eligible recipient that is awarded a grant  
20 or cooperative agreement under this section  
21 may use the funds for—

22                   “(i) training programs for family  
23 caregivers to assist such family caregivers  
24 in making informed decisions about respite  
25 care services;

1                   “(ii) other services essential to the  
2                   provision of respite care as the Secretary  
3                   may specify; or

4                   “(iii) training and education for new  
5                   caregivers.

6                   “(2) SUBCONTRACTS.—Each eligible recipient  
7                   that is awarded a grant or cooperative agreement  
8                   under this section may use the funds to subcontract  
9                   with a public or nonprofit agency to carry out the  
10                  activities described in paragraph (1).

11                  “(g) TERM OF GRANTS OR COOPERATIVE AGREE-  
12                  MENTS.—

13                  “(1) IN GENERAL.—The Secretary shall award  
14                  grants or cooperative agreements under this section  
15                  for terms that do not exceed 5 years.

16                  “(2) RENEWAL.—The Secretary may renew a  
17                  grant or cooperative agreement under this section at  
18                  the end of the term of the grant or cooperative  
19                  agreement determined under paragraph (1).

20                  “(h) SUPPLEMENT, NOT SUPPLANT.—Funds made  
21                  available under this section shall be used to supplement  
22                  and not supplant other Federal, State, and local funds  
23                  available for respite care services.

1   **“SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**  
2                                   **TER.**

3           “(a) ESTABLISHMENT.—The Secretary shall award a  
4   grant or cooperative agreement to a public or private non-  
5   profit entity to establish a National Resource Center on  
6   Lifespan Respite Care (referred to in this section as the  
7   ‘center’).

8           “(b) PURPOSES OF THE CENTER.—The center  
9   shall—

10           “(1) maintain a national database on lifespan  
11   respite care;

12           “(2) provide training and technical assistance  
13   to State, community, and nonprofit respite care pro-  
14   grams; and

15           “(3) provide information, referral, and edu-  
16   cational programs to the public on lifespan respite  
17   care.

18   **“SEC. 2904. REPORT.**

19           “Not later than January 1, 2007, the Secretary shall  
20   report to the Congress on the activities undertaken under  
21   this title. Such report shall evaluate—

22           “(1) the number of States that have lifespan  
23   respite care programs;

24           “(2) the demographics of the caregivers receiv-  
25   ing respite care services through grants or coopera-  
26   tive agreements under this title; and

1           “(3) the effectiveness of entities receiving  
2           grants or cooperative agreements under this title.

3   **“SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.**

4           “There are authorized to be appropriated to carry out  
5 this title—

6           “(1) \$90,500,000 for fiscal year 2006; and

7           “(2) such sums as are necessary for fiscal years  
8           2007 through 2010.”.

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